Opinions Concerning Access to Health Insurance in Illinois: A Report of Focus Group and Key Informant Interviews

Prepared for the Illinois Department of Insurance State Planning Grant

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I. Executive Summary

In 2000, Illinois was one of twenty states receiving grants from the U.S. Department of Health and Human Services to study the health insurance gap within the state in an effort to achieve consensus with stakeholders and key constituents on ways to close this gap. Quantitative and qualitative research methods were employed to study the uninsured in the State of Illinois and examine solutions employed by other states in order to tailor solutions specifically to Illinois for closing the health insurance gap.

This report summarizes the results of numerous focus groups and interviews with key informants that were conducted during the spring and summer of 2001 around the State of Illinois. Focus group members consisted of seven constituencies with a stake in the problem of the un and underinsured: small business owners offering health insurance, small business owners not offering health insurance, representatives of health and social service agencies, members of the insurance industry, medical providers, members of local governments, and the uninsured themselves. Multiple focus groups within each constituency were conducted across five geographic areas of the state. Most focus group participants participated in a nominal group process as well, a technique that allowed them to brainstorm ideas for solutions to address all or part of the factors that affect the health-insurance gap. Interviews were conducted with high profile individuals in business, health and social services, government, and community activism.

Using these strategies of interview and group process, we were able to compile themes that emerged within and across constituency groups about specific experiences stemming from the health insurance gap as well as attitudes towards existing public and private mechanisms for addressing that gap. We summarized these themes in a

presentation to the July 10 Illinois General Assembly Process. The focus group results were intended to provide texture and nuance to the quantitative findings and literature reviews that made up a large portion of the framework from which the Illinois Assembly Process operated. The focus group and interview formats were similar, and were based on the primary set of questions addressing the mandates of the Illinois State Planning Grant. These questions are as follows:

- What are the effects and ramifications of not having health insurance?
- What factors account for why people do not possess health insurance?
- How are people who lack health insurance getting their health needs met?
- What are the perceptions, experiences, and expectations of people working with or utilizing public health insurance programs such as Medicaid and KidCare?
- What factors account for why some businesses provide health insurance to their employees while others do not?
- What types of mechanisms or incentives would help small businesses in their ability to offer health insurance to employees?
- What should be a minimum health insurance benefit that all Illinois residents should have access to?
- By what means could health insurance be made available to all Illinois residents
- What would be effective ways to raise awareness about the availability of new health insurance products that are designed to close the health insurance gap?

This report reflects the discussions, opinions, themes and contradictions offered by individuals on the front line of the health insurance gap in the state of Illinois.

II. Introduction to the Study

In October 2000, The Illinois Department of Insurance received a grant from the U. S. Department of Health and Human Services to study the health insurance gap (i.e., people who do not have health insurance either through private or public sources) in the State of Illinois and to achieve consensus from key constituents and stakeholders for plans and ideas to close this gap. In addition to extensive survey research conducted to understand the characteristics of people who do not possess health insurance, qualitative research was conducted to explore the opinions and reactions of various groups toward the health insurance gap and to gain ideas for closing the gap. Qualitative research is used for the purpose of gaining "rich descriptive" information that can illustrate problems and opportunities, and to put a human face or story onto technical statistical information garnered from survey research. Furthermore, with qualitative research, questions can be explored in more detail, and individual cases can be thoroughly examined in order to shed light on the issues that inform our understanding of the health insurance gap.

We utilized two qualitative research techniques: focus groups and key informant interviews. Focus groups are structured group interviews consisting of individuals who share common characteristics. Although focus group participants may not know one another, they view themselves as similar to other group participants and thus are able to reflect on similar circumstances when forming opinions and reactions. We formed seven different types of focus groups: small business owners offering health insurance, small business owners not offering health insurance, representatives of health and social service agencies, members of the insurance industry, medical providers, members of local governments, and the uninsured themselves. Multiple focus groups within each group

type were conducted across five geographic areas of the state (to be reviewed in section III).

The purpose of the focus groups was to provide texture and nuance to the quantitative findings and literature reviews that made up a large portion of the framework from which the Illinois Assembly Process operated. Moreover, the focus group sessions represent a medium for various constituencies and stakeholders to have a voice in the planning process. Although focus groups do not represent a data source from which broad inferences can be made, they still provide that important "insider's story" that can otherwise become lost in a quantitative maze of tables and figures. Group members gave us their own personal stories about the health insurance gap -- why it is difficult to afford health insurance, why it is difficult to serve those with or without health insurance, why it is difficult to provide health insurance to all state residents. They also discussed frustrations and opportunities in working with public and private health insurance programs, opinions about minimum health insurance plans, and provided ideas for closing the health insurance gap.

In addition to the focus groups, key informant interviews were conducted with high-profile stakeholders and constituents across the State of Illinois, such as insurance industry, business/labor, and social services representatives. These used similar questions as the focus groups interviews. One-on-one interviews were conducted with high profile individuals to protect their concerns for speaking freely in the presence of others.

III. Method of Research

A. Focus Groups and Nominal Group Process

Focus groups were conducted in five non-overlapping and exhaustive regions of the state (Southern Illinois, Central Illinois, Cook County, the Collar Counties, and Northwest Illinois), and were comprised of small business owners offering health insurance, small business owners not offering health insurance, representatives of health and social service agencies, members of the insurance industry, medical providers, members of local governments, and the uninsured themselves. Table 1 provides a breakdown of the number of groups conducted of each type:

Table 1: Focus Group Characteristics

Type of Group	Number of Groups Conducted	Regions Conducted	Average Number of Participants/Group
1. Businesses without HI	2	Central Southern	5.5
2. Business that offer HI	6	Northern Southern Cook County	5.2
3. Health Care Providers	4	Cook County Collar Counties Northern Southern	6
4. Insurance Representatives	3	Central Northern Southern	4
5. Health and Social Service agents	4	Central Cook County Collar Counties Southern	5
6. Local Government Representatives	2	Cook County Southern	5.5
7. Uninsured	6	Central Collar Counties Northern Southern	4

In each focus group we asked a series of pre-determined questions intended to stimulate discussion among group participants about their experiences stemming from the problem of un- and under-insurance in Illinois (see Appendix A). A note-taker compiled detailed notes during each focus group, and each session was tape-recorded, making it possible for note-takers to double check and augment their notes as needed.

These notes then formed the backbone of our analysis. Each literal or paraphrased comment by focus group participants was placed in a database, along with group type and the question to which it was a response. Two research assistants read each comment and independently created a series of themes into which the comments were organized. When this process was complete, the entire focus group team met to review and fine tune the categorization scheme in order to insure a reasonable degree of "inter-rater" reliability. These themes were then entered into the database with the corresponding comments. Themes were augmented or added as information from subsequent focus groups was added to the database. In this fashion, we were able to organize the database, and hence our analysis, by theme, focus group type, question, or region of the state.

We organized the literal or paraphrased quotes into thematic categories broken down by question type and noted the type of group from which the quote/phrase emanated. We selected quotes for the resource guide that we felt best captured the "spirit" or intent of the theme. In some cases, several quotes are included under a theme to illustrate the prevalence of a particular point of view, or alternatively the diversity of opinions regarding some theme (e.g. whether mental health benefits should be included in

a minimum benefits plan). Only themes that were voiced more than once by a particular type of group were included in this analysis. The Focus Group Resource guide (see Appendix B) contains the entire set of thematically organized quotes and phrases. This report expands on the themes that were of primary interest to the State Planning Grant.

We also included a "nominal group process" during most of the focus group sessions (with the exception of the uninsured). Participants were asked to write down five potential solutions for closing the health insurance gap in Illinois. These recommendations could be broad (e.g. make people more accountable for their health insurance status) or more specific (e.g., expand KidCare to cover parents). Participants were then asked to state their primary recommendation, which we recorded on a large post-it. Depending on time and the number of participants, each participant had the opportunity to state 2-3 recommendations. In this manner, 10-15 ideas were generated, discussed, clarified and adapted by group members, as they deemed appropriate. Participants were then asked to independently rank their top five choices. We compiled the ranks across group participants and arrived at a final consensus ranking. We entered the top five ideas from each group into a database, and determined emerging themes. These themes and supporting ideas are included in the Focus Group Resource Guide.

B. Key Informant Interviews

Fifteen personal interviews were conducted with individuals knowledgeable of the problems of insurance and lack of insurance in the State of Illinois. People interviewed included: CEOs, COOs of large insurance companies, Human Resource specialists, health care providers (both large hospital systems and rural clinic providers),

representatives from leading corporations in the State of Illinois, small local firms, union representatives, a large faith-based group, a government agency representative, and state legislative leaders (one state representative and one state senator). In addition to representing different corporations and agencies, the individuals were located throughout Illinois, representing a geographically diverse interview sample.

The purpose of the personal interviews was to gather more specific opinions regarding the problems and solutions related to the uninsured population in a way that would not be threatening to the interview subjects. For example, a COO from a large insurance company might have been reluctant to voice her or his opinions publicly, even in a focus group setting. However, in the setting of a personal interview with anonymity guaranteed, a more free flowing discussion was made possible. Professor Paul Sarvela and Mr. Dan Shannon of SIUC conducted the personal interviews.

The project team identified the personal interview subjects, with special consultation from agencies and organizations. Once identified, Ms. Madelynne Brown sent a letter to the CEO, describing the project and asking for participation in the interview. Follow-up calls were then made to the CEO (or individual designated by the CEO) and, the interview time was sent up. Interviews were conducted either on-site or via the phone. Human Subjects issues were discussed with each interviewee and informed consent was received before proceeding with the interview.

Interview questions varied slightly by particular subject, but core issues covered included:

1. Perceptions related to why people are currently uninsured.
2. Perceptions related to why employer-based coverage is decreasing.

3. Identification of incentives that can be used to get small companies and businesses to help cover their employees.
4. Methods the insurance industry, along with state government and employers, can use to increase coverage.
5. Characteristics of the ideal insurance program.
6. Statewide cost estimates of providing the ideal program to those currently uninsured.
7. Ideas concerning the best partnering structure to achieve the goals of statewide coverage.

IV. Research Findings - Focus Groups & Personal Interviews

Below we present the findings based on the primary set of questions addressing the mandates of the State Planning Grant. These questions were:

1. What are the effects and ramifications of not having health insurance? (Lack of health insurance effects)

2. What factors account for why people do not possess health insurance? (Why people lack health insurance)

3. How are people who lack health insurance getting their health needs met? (How medical needs are being met)

4. What are the perceptions, experiences, and expectations of people working with or utilizing public health insurance programs such as Medicaid and KidCare? (Perceptions of public health insurance)

5. What factors account for why some businesses provide health insurance to their employees while others do not? (Why businesses offer health insurance and their struggles to maintain it; Reasons why small businesses don't offer health insurance)

6. What types of mechanisms or incentives would help small businesses in their ability to offer health insurance to employees? (Mechanism that would help small businesses)

7. What should be a minimum health insurance benefit that all Illinois residents should have access to? (Minimum benefit)

8. By what means could health insurance be made available to all Illinois residents (Funding mechanism/affordability)

9. What would be effective ways to raise awareness about the availability of new health insurance products that are designed to close the health insurance gap (Raising awareness/marketing).

In the sections that follow, the themes that emerged for each of these questions are described and delineated by the type of group(s) from which the theme emerged. Representative quotes are provided.

A. Lack of Health Insurance Effects

All types of groups offered opinions about the ramifications of not having health insurance. Many of the themes that emerged were straightforward.

1. Delaying treatment. Typically the uninsured focus group participants stated that they simply put off seeking medical care until a problem becomes acute or when they can no longer ignore treatment.

Representative quote: *I would rather tough it out rather than lose 1/2 year's salary for medical treatment.* (Uninsured person)

2. Affecting daily living choices. In addition to delaying treatment, uninsured participants told us about the struggles they contend with day to day in deciding how their few resources will be spent -- for example, do they put food on the table or do they get a long overdue medical check-up.

Representative quote: *I have to make choices about going to the doctor or buying diapers, etc.* (Uninsured person)

3. Use of emergency rooms. For uninsured people, the emergency room is often the first and only point of contact with a health professional. The expenses that are incurred are often very high, and payments have to be stretched out over a long period of time.

Representative quote: *My son was so sick that I took him to the emergency room. The bill was $1000 and it took a year to pay it off.* (Uninsured person)

4. Risking financial security. An uninsured person lives with the fear that one catastrophic medical event or accident could ruin them financially. They could lose all their hard-earned assets, such as a house, just to pay one bill.

Representative Quote: *Lack of health insurance affects people's lives in other ways. Some families break up because they owe too much.* (Uninsured person)

5. Rationing payments and treatment. The uninsured and those who work with uninsured individuals and families know that they have to stretch their dollars as far as they can go. Therefore a common strategy is to pay only portions of their medical bills, stretching them out over longer periods of time. Another form of rationing involves taking only a portion of prescribed medications or sharing them with other members of the household.

Representative quotes:

- *We can sometimes afford some health care but we really have a difficult time affording a hospital stay. I pay the people who have to be paid. Hospitals just have to wait.* (Uninsured person)
- *Those who must take their prescriptions regularly (diabetics, high blood pressure) end up sharing their medication with their spouses or family members.* (Local government official)

6. Treated poorly by others. Because of the stigma of being poor or near poor, those who lack health insurance often perceive that they are receiving inferior treatment by health care professionals, their staff, or by public sector/social service agents with whom they must interact to get their health needs met.

Representative quote: *They treat me so poorly at the hospital that I try never to go* (Uninsured person)

7. Falling in and out of the gap. Many uninsured people go through spells of uninsurance that may last for a few years to a few months. This may be due to changes in jobs where one employer offers health insurance but the next does not, being laid off by an employer who offered health insurance, but not qualifying (or unable to afford) COBRA, moving from student (with health insurance) status to non-student status (without health insurance), or moving out of public aid eligibility (e.g., a new mother who had been covered under KidCare while pregnant, but is no longer covered after the child is born). The transient status of health insurance gaps is a source of stress and frustration. The uninsured often live their lives in the hope that nothing serious will happen to them during a spell when they are uninsured.

Representative Quote: *I've been on and off health insurance for several years. My husband works for a small company and there have been times when we really could not afford it. We have been told that we make too much to qualify for public aid. We fall through the cracks.* (Uninsured person)

B. Why people lack health insurance

Reasons for not having health insurance were categorized into four overarching themes: (a) individual access problems; (b) employment-related linkages; (c) inability to access public health insurance programs; (d) Medicaid gap. Sub-themes within each of these categories are described below.

1. Individual access problems

a. Affordability. The most common response we heard from almost every type of focus group participant was that the cost of health insurance premiums are

simply too high to afford without some form of subsidy assistance (e.g., employer-based subsidies). Insurance representatives lamented that the cost of health insurance premiums are so high because of the skyrocketing costs of medical care and the losses incurred from those who do not pay their medical and/or insurance bills.

Representative quote: *People who are struggling to survive financially can't see putting out $150 per mo. for insurance.* (Health and social service agent)

The cost itself; being driven by higher medical costs, cost shifting, making the product so good that no one can afford it. (Insurance representative).

Cost is a huge factor (Rural health clinic administrator)

b. Pre-existing conditions. Because of the exclusions or long waiting periods for people diagnosed with a medical condition before they obtain health insurance, many people are simply ineligible for health insurance. This problem is compounded by the apparent closure/wait list of the Illinois high-risk pool insurance program (ICHIP).

Representative quote: *I have a friend who could not transfer her health insurance to her new job. Health insurance companies do not pick someone up if there is a preexisting condition.* (Local government official).

c. Cultural barriers. People who are not members of the majority culture, i.e., those who are not White or native English speakers experience difficulties in accessing health insurance above and beyond the conditions outlined above due to language barriers, fears of discrimination or poor treatment based on their minority status or cultural practices that are at odds with the normative expectations for seeking health

insurance information. For example, some cultural practices may shun treating medical conditions. Moreover, immigrants often live in isolated communities and may not know where to find information about health insurance, or they may fear that accessing the health care system may jeopardize their immigrant status (e.g., fear of deportation).

Representative quote: *Transient populations (migrant workers; those fluctuating between employment and unemployment)– don't get enrolled in programs because they're not around long enough.* (Health and social service agent)

d. Individual choice. A few uninsured individuals stated that they chose not to purchase health insurance because they felt they were healthy enough to incur the risk and that they had other priorities. This sentiment was expressed more often, however, from people in other types of groups rather than from the uninsured themselves.

Representative quote: *Some think they just don't need it, especially young people who haven't been sick before. Males are more likely to feel this way than females.* (Health and social service representative).

2. Employment linkages. Most Americans obtain their health insurance through their employers who typically pick up some or all of insurance premium. This link between employer and health insurance, therefore, means that some people will be without health insurance because they are unemployed, or their employer, for a variety of reasons, doesn't offer health insurance. There were several sub-themes related to employer-based linkages.

a. Employer doesn't offer health insurance. A common sentiment expressed by various focus group participants was that businesses deliberately employ a part-time or contingent (e.g., contract or seasonal workers) workforce in order to avoid offering health insurance benefits. Employers and other professionals believed that the health insurance industry charged rates that were too expensive for small employers to afford.

Representative Quotes:

- *Since employers don't have to provide health insurance to part-time employees, some of them choose to hire part-timers* (Health and social service agent).
- *In the effort to move people from welfare to work, we have often moved people to minimum wage jobs with employers who do not offer insurance.* (Provider)

b. Portability concerns. Although COBRA provides a mechanism for people to keep their employer-based insurance for a period of time when they leave a job, many people cannot afford this option (often the individual pays the entire cost of the premium), they exhaust this option before finding new employment with health insurance benefits, or they were ineligible for COBRA due to the seasonal nature of their jobs.

Representative quote: *Seasonal and immigrant employees are not usually covered because of the hassles of switching plans as they move from jobs or locations* (Provider).

c. Lack of in-network providers. Employers, especially those in less populated areas, who want to find an affordable health

insurance program for their employees found that the most affordable plan had no or a very limited choice of providers in the health insurance network located where employees live.

Representative quote: *In some cases, health insurance is available but no providers are present in the area.* (Health and social service agent)

d. Employer-insurance expectancy. There were many opinions expressed that our society has created an expectancy that health insurance is the responsibility of employers, not of individuals. Thus, individuals do not take adequate measures to plan and budget for health insurance when they are unable to obtain employer-based health insurance.

Representative quote: *Our society links health care coverage with employment. This is a problem because people are not taking responsibility for covering themselves*. (Provider)

3. Public health insurance inaccessibility. There were many sentiments expressed that more people could be served by public health insurance programs such as Medicaid or KidCare, but these programs were functionally unavailable because of the red-tapes and hassles of accessing or working with these programs, or due to lack of awareness. There were several sub-themes.

a. Long waiting periods for immigrants. Some voiced concerns that one reason why immigrants lack health insurance is because of the long (5 year) wait period to be eligible for public health insurance once legal residence (e.g. green card) has been established.

b. Community development programs thwarted by red tape. We spoke with members of various private or community development programs who had been working on plans to provide access to health care or health insurance for medically under-served populations. They spoke of many frustrations they experienced in trying to coordinate their efforts with existing state rules and regulations.

Representative quote: *Our chamber of commerce tried to do a small business coverage plan, but have not been able to do it because of bureaucratic and legislative problems. Tried to "adjust" to rules, but were thwarted* (Health and social service representative).

c. Perception of people who misuse public health insurance programs. Several focus group participants across several types of groups were concerned about the apparent misuse of public health insurance programs and other forms of public aid. Some were of the opinion that a reason for the high cost of health care, as well as the stigma for accessing public health insurance is because some people misuse or take advantage of the system.

Representative quote: *I also think people take on the attitude that if I get sick other people are going to help me pay.*(Uninsured person)

d. Working poor don't qualify for Medicaid Several personal interview subjects commented on problems related to the working poor being unable to qualify for Medicaid, yet, did not have the funds to pay for private insurance.

Representative quote: *I sense that there is a gap between where Medicaid cuts out and low wage earners ability to pay for insurance because they have*

jobs that don't pay health insurance or require too high a premium for the worker to afford. (Faith-based administrator)

C. How health care needs of the uninsured are being met

We wanted to hear how people who are caught in the health insurance gap take care of their health and medical needs. Such information would shed light on the adequacy of the health care safety net in Illinois as well to learn more about the consequences of not having health insurance. These questions were asked to our groups of uninsured people, health care providers, health and social service agents, and local government representatives. The following themes emerged.

1. Home remedies. In attempt to solve health-related problems at a minimal cost, many uninsured focus group participants stated that the relied on home remedies, typically using products that are found around the house or can be purchased inexpensively without a prescription.

2. Ignoring or delaying treatment for health problems. To the extent that the uninsured are reluctant to seek routine health care or ignore or delay treatment for medical ailments, health problems escalate into more serious conditions.

Representative quote: *Most people go for health care only when they are so sick that they cannot treat the problem themselves. Their first encounter with the system is the emergency room.*(Health and social service agent)

Representative quote: *Some just don't seek medical help for procedures they need* (Elected official).

3. Use of the emergency room. The uninsured often use the emergency room as their first and sometimes only point of service for medical treatment. They believe that emergency rooms are the only place they cannot be denied treatment due to an inability to pay.

Representative quote: *Many go to the emergency room for health needs because they don't have health insurance, and don't qualify for Medicaid* (Health and social service agent)

4. Free clinics, public health centers, and community programs. When we asked people how the uninsured are getting their medical/health needs met, several noted that they or others they knew used free or reduced-fee clinics. Often there were others in the group who may not have known about such facilities. At the end of the focus group, participants exchanged such information with one another. Several people commented that it would be helpful to have a directory of such services in a community.

Representative quote: *Free clinic in Elgin – for indigent patients who can't pay anything – it's [staffed by] volunteer physicians and [other] volunteers – expansion is opening in July- sliding scale payment*. (Health and social service representative)

5. Charity from doctors. Several uninsured focus group participants as well as several health care providers commented that some doctors provide a certain amount of free or reduced-fee service to uninsured patients. The uninsured often knew of a doctor or dentist who would accept a nominal fee, or would try to provide patients with free prescription samples as much as possible. Many providers commented that they find

it easier to give their services away for free than to try to deal with Medicaid reimbursement processes, but are worried about liability issues.

Representative quote: *It's just easier to provide the service for free than to mess with all the red tape.* (Health and social service representative).

D. Perceptions of public health insurance programs.

As the state-supported public health insurance network (e.g., Medicaid, KidCare, ICHIP) is likely to be an integral part of solutions to closing the health insurance gap, we wanted to gain impressions and opinions about these programs, both from the perspective of potential clientele and as well as from providers and social service agents who work with such programs. There were several themes associated with perceptions of public health insurance programs, which were broadly categorized as (1) reasons for not participating in public health insurance; (2) problems experienced in working with public health insurance; and (3) positive experiences with public health insurance. Sub-themes within each category are described below.

1. Reasons for not participating in public health insurance.

a. Individual barriers. There were a number of reasons why individuals did not utilize public health insurance resources such as Medicaid, KidCare, ICHIP, or various veterans' benefits (e.g., CHAMPUS). Many did not want the stigma of being a public aid recipient and feared being treated as a second-class citizen by health care professionals or their staff. Others noted that they could not find doctors or other providers who would take Medicaid/KidCare patients (Lack of Access to Providers.) Some noted cultural barriers, such as not having sufficient language skills to obtain information about where to seek medical attention by providers who accept public health

insurance, or they feared risking their immigration status if they utilized such services. We heard from several types of people (e.g., providers, social service agents, insurance agents) who complained about the long and complicated application process for KidCare, especially, although several of the parents whose children are on KidCare did not think the process was complicated. For those with pre-existing conditions who could obtain private health insurance, we heard complaints that the Illinois high-risk pool insurance program (ICHIP) was difficult, if not impossible to get into, or they were not aware of this program. Finally, lack of awareness of being eligible for various public health insurance programs was a common remark. For example, many people including some elected government officials had not heard of the KidCare program. Some parents whose children were on KidCare claimed that they had to do the research on this program and inform their social services representative about the program.

Representative quotes:

- *Maybe a newspaper article that explains about KidCare, and other public programs would help people better understand why some need it*. (Uninsured person)
- *I don't want to be lumped together with those who are freeloading.* (Uninsured person)

b. **Provider barriers**. Many health care providers mistrusted government-sponsored health insurance programs. They complained that state bureaucrats who managed such systems had little understanding of the local conditions under which the provider was operating, or little understanding of the medical conditions

upon which the provider was operating. Therefore, some providers were reluctant to accept patients with public forms of health insurance.

Representative quote: *Physicians don't have enough faith in the programs to support expanded statewide efforts.* (Provider).

2. Problems experienced with public health insurance. Despite barriers to utilizing public health insurance programs (listed above), many participants were either primary recipients of such benefits or were part of the provider or tertiary network for such benefits. They spoke candidly about various problems and frustrations they experienced with public health insurance programs. Themes are categorized by individual- and provider-based concerns.

a. Individual concerns. We heard examples of poor treatment by the "system". For example one KidCare parent felt as if she that because she was a public aid recipient, that health care staff assumed she engaged in poor health behaviors, such as drinking or smoking. Others felt ashamed to be on public health insurance because of the perception or understanding that some people misuse or abuse the system and create a poor reputation for others. Finally, many people felt that the *benefits* of public health insurance were inadequate because it may not pay for mental, dental or vision benefits adequately.

Representative quotes:

- *Some are 2nd and 3rd generation welfare, so they know the system and how to play it*. (Provider)
- *I've been treated as if I were a smoker or drinker. I'm neither. I resent the treatment*. (Uninsured person)

- *Mental health is ignored across the board. Period*. (Health and social service representative).
- *It is a problem when we refer someone to a specialty care provider* (Rural health director).

b. **Provider concerns**. Providers and related professionals who provided services to public health insurance beneficiaries expressed a number concerns when dealing with the public health insurance infrastructure. In particular, they complained of a burdensome bureaucracy. For example, rules for complying with regulations seemed to change without notice – what was acceptable practice six months ago, was no longer valid. It also seemed that providers had less and less autonomy in making medical decisions despite their own concerns for keeping costs low. For example, one provider lamented that a Medicaid patient who presented with problem A was found to also have problem B. The physician couldn't treat problem B while treating problem A unless the patient was discharged from the hospital and re-admitted. A common concern was that Medicaid (and related public programs) had very slow and unreliable reimbursement practices. "Low, slow, or no pay" was a common mantra. Referring patients to specialists was complicated by the fact that there often wasn't an appropriate specialist in the area who was a qualified Medicaid provider. Unrelated to the Medicaid bureaucracy, but nonetheless a concern of Medicaid providers was a sense that Medicaid and/or free-clinic beneficiaries were not committed to therapeutic regimens or to maintaining appointments. One dental provider commented that a free dental clinic he staffed had to close not due to lack of funding, but due to poor patient commitment to the center and the care they received.

Representative quotes:

- *It costs more to use staff to do all the paperwork, than to just do the care for free, and use the staff for something else. Many practices aren't profit driven in the first place.* (Health and social service representative)
- *No longer possible for family practitioner to be family practitioner, doesn't have time to spend sufficient time with patient [due to hassles of dealing with public insurance programs.* (Provider)
- *The no-show rate from the public aid population is huge. This adds to costs.* (Provider)

3. Positive experiences with public health insurance. Despite many complaints and frustrations with public health insurance voiced from providers, recipients, and other agents, we also heard many positive remarks.

a. Good service/coverage. There was a strong sense that public health insurance was a critical component of the health care safety net and that it was often a lifesaver. In addition, both providers and recipients alike noted that the level of coverage in Medicaid and KidCare was very good – better than many private insurance plans, and that reimbursement was often better from public health insurance programs than from private ones.

Representative quote: *The program of Medicaid and KidCare are good and helpful for those we know who qualify.* (Uninsured person)

b. Minimum hassles with KidCare enrollment. Despite many complaints by providers, social service agents, and insurance agents that the KidCare

form was long and complicated, parents whose children were enrolled in KidCare told us that the form was not forbidding. They were grateful that the program existed.

c. Saved from financial ruin. Without public health insurance, several uninsured individuals told us that they would have surely lost all of their personal assets for the cost of one or two catastrophic medical bills. Saving one's livelihood was more important than being ashamed of public assistance.

Representative quote: *I had a man tell me that I should not accept welfare if I were a "true man." When I was about to lose my home I decided that stigma was not important.* (Uninsured person)

d. Right to public health insurance. Many Medicaid/KidCare recipients told us that they did not feel ashamed of participating in public health insurance. They had been paying taxes toward such programs and felt that when their circumstances warranted, they should have the right to such benefits.

Representative quote: *Welfare is paid by taxes. I paid taxes with my job so if I were to lose it, I feel entitled to it* (Uninsured person).

e. Provider Business Perspective Several providers were satisfied with working with public aid programs.

Representative quote: *The programs are fine* (Rural health program director). *We have no real problems with Medicaid* (Hospital system CEO).

E. Why businesses offer health insurance and their struggles to maintain it.

The majority of American citizens have health insurance through their employers who pay part or all of the premiums. Although most large employers offer health

insurance benefits to employees (typically only full time employees, however), small employers (e.g., under 50 employees) struggle to afford, let alone maintain this benefit. The cost of health insurance benefits to small employers is particularly difficult because (1) they often don't have the profit margin to absorb high premiums; (2) they get less favorable rates than large-group employers who can distribute and absorb risk more easily; and (3) they often do not have benefit specialists on staff who can research the best rates and plans for the company. Despite these obstacles, many small employers offer health insurance to their employees, and we wanted to learn their reasons for doing so.

1. Attract and retain high quality employees. Employers emphatically agreed that attracting and retaining high quality employees was the primary reason why they offered health insurance. Many believed it gave them a competitive advantage over competing employers for qualified, loyal employees.

Representative Quote: *We offer health insurance to attract high quality employees and be competitive with other companies* (Insurance managers for a large corporation).

2. Self-coverage. Another reason for offering health insurance benefits to employees was for the owner to be able to obtain health insurance for him or herself. This reason was salient among owners who were unable to obtain individual private insurance because they had high health risks or pre-existing conditions.

3. Moral obligation. Finally, several employers felt that providing health insurance to employees was the right thing to do. They viewed their employees as members of a family. Often, employees had worked with the company for several years, and the employer would never think of cutting back on this benefit. Furthermore,

employers felt grateful that their employees were covered by insurance when a catastrophic event occurred, even if such an event created burdensome rate increases for the company.

Representative quote: *We had an employee with a brain tumor whose bills must have been enormous, but couldn't imagine not having insurance for him. The costs and benefits are incalculable. Can't put a dollar value on this.* (Business owner who offers health insurance).

4. Rate increases and affordability. Maintaining health insurance benefits is a constant struggle for small business owners. We were told that rates would increase by double digits annually. Employers will spend a great deal of time researching the best and most affordable plans. This is time taken away from other duties of their business.

5. Expectations and naivete of employees. Although employers clearly valued the business purposes of offering health insurance, and often felt a moral obligation to do so, they were frustrated by employees' lack of understanding of the cost and hassles to secure this benefit. Furthermore business owners stated that employees expect them provide health insurance, without a good understanding of the hardship this causes for the employer or the true monetary value of this benefit.

Representative quote: *I feel that some employees don't really have an appreciation for getting heath insurance offered to them. They don't know just how much it costs.* (Business owner)

F. Why businesses don't offer health insurance.

Despite the business and personal advantages of offering health insurance, many businesses, especially small ones do not offer health insurance. We wanted to gain a better understanding of why businesses did not offer health insurance to their employees.

1. Affordability. By far the most common reply was that health insurance was simply too expensive and the small business owner did not have the means to afford to offer this benefit and remain viable. Some business owners who had previously offered health insurance had to discontinue this benefit because rate increases in insurance premiums became too high for the business to absorb. Some business owners pointed to what seemed like unnecessary and costly mandates that drove up the price of health insurance. For example, a small business owner with two or three long-time employees felt it was unnecessary to pay for maternity benefits when all of his employees were beyond the age of needing this benefit. Another factor that seemed especially unfair to the small business owner was the impact that one high health risk employee could have on the employers group rates. Larger businesses can absorb the increase in risk ratings of a few high-risk employees, but this is especially difficult for the small employer. Representative quotes:

- *My business has increased by 5-10% the past few years but my insurance costs rose by several more percent, thus, I no longer carry health insurance.* (Business owner).
- *The illness of one employee raised the costs very high for all of the other healthy employees.* (Business owner)

2. Employees insured elsewhere. Small business owners who may have only a few employees often told us that their employees were insured elsewhere, typically by their spouses, therefore they did not need to offer health insurance.

3. Employees choose not to accept employer's health insurance benefit. Also, although not a frequent remark, some employers stated that their employees turned down their health insurance offer or stated that they did not want health insurance benefits. This remark coincides with some uninsured persons' statements that they would turn down employer-based health insurance if the cost of the premium was too high, or they would rather spend the extra money elsewhere.

Representative quote: *I paid an employee more money so that he could purchase his own health insurance but he chose to spend the extra money elsewhere.* (Business owner)

4. Business employs part time or seasonal workers. Several focus group participants, not necessarily small employers themselves, remarked that businesses that primarily employ part time or seasonal workers do not offer health insurance to their employees. Some participants even went so far as to say that some businesses, not necessarily small ones, deliberately employ a large part-time work force in order to avoid paying such benefits. Others stated that employers who typically employ students as part-time employees believe that these students are either covered by their parents' plans or by a school plan, but this was not always the case.

Representative quote: *We have several part-time workers. Some are part-time students and thus, they don't have school insurance. That's a real concern to us.* (Business owner).

G. Mechanisms that would help small businesses.

Although more specific ideas for closing the health insurance gap were gathered in the nominal group processes (described in a later section of this report), we asked small business owners and insurance agents who help small businesses obtain health insurance for ideas for helping business owners afford this benefit.

1. Purchasing groups. Business owners liked the idea of being able to join together with other business owners to form a purchasing cooperative and thus be able to compete for better health insurance rates. It appeared that most small business owners were not aware of problems that have plagued other purchasing group initiatives, such as adverse selection (i.e. the purchasing group attracting a high risk pool and becoming a disincentive to low risk individuals who could find better rates with an individual plan), but they seemed to be willing to work toward a solution that might make purchasing pools a viable option. Some business owners suggested that the state should create one large purchasing pool for all small businesses.

Representative quote: *If Illinois could offer a small business plan that would cover many employees statewide that might allow us to afford it.* (Business owner)

2. Tax incentives. Small business owners had favorable attitudes toward tax incentives especially if it allowed them to earn a tax credit for the cost of providing health insurance to employees. However, some believe that a tax break does not help employers provide coverage.

Representative quote: *A direct individual tax credit to pay for health insurance premiums might work really well and reduce the [number of] uninsured.* (Insurance agent)

Representative quote: *Employers already get a tax break; however, this is not overcoming the increasing costs of health insurance coverage* (Insurance company executive)

3. Access to providers in the area. Some small business owners were attracted to managed-care forms of insurance because of the low costs, but were frustrated if the choice of providers in a particular network was low or nonexistent. This frustration was particularly felt by small businesses located in rural areas.

Representative quote: *We had to separate our health insurance from the parent company because of the complications due to changes in PPOs etc., so, we're less flexible and powerful than we use to be.* (Business owner)

H. Minimum benefit

To the extent that either a single program or a set of programs and initiatives would be developed to cover all Illinoisans who currently lack health insurance, there needs to be consensus on what level and range of benefits should be offered. We asked all focus group members their opinions on what should be the minimum benefit level for health insurance. There appeared to be two opposing "top-of-the-head" responses: bare minimum, catastrophic only, and comprehensive plans that cover major medical, preventative, and expanded benefits, such as dental and mental health coverage. Upon further discussion and reflection most focus group participants agreed that a good basic

plan that emphasized preventative, maintenance, hospitalization (catastrophic), and dental benefits would constitute a good minimum benefit. However, there were a number of issues pertaining to minimum benefits that various focus group members wanted to emphasize. The follow themes are divided into three categories: (1) issues to consider in deciding a minimum benefit; (2) general plans; and (3) specific benefits.

1. Issues to consider. Focus group participants emphasized that minimum benefits should entail a low deductible, or other means of keeping the benefit affordable, such as having a sliding scale, based on income or ability to pay. In addition, focus group participants were concerned about keeping the cost of health care down, emphasizing the need to ration and prioritize health care services holding to the belief that health care costs are so high because the American public expects gold standard treatment. Furthermore, there was a strong belief that public health insurance programs, like other forms of public assistance, can be misused. For example, recipients of public health insurance are perceived to have a disincentive to find employment that offers health insurance, or they expect high-cost services at the taxpayers expense when such services may not be medically warranted. Therefore participants wanted to be sure that public programs were monitored for potential misuse and abuse. Business owners were particularly concerned about *problems with mandates,* such as coverage for procedures like in-vitro fertilization or other types of "personal choice" procedures, and being penalized for pre-existing conditions. Small business owners were sensitive to the fact that they were singled out by the insurance industry to provide medical histories on all employees whereas larger employers did not have this burden.

Representative quotes:

- *Problem in defining what health care should be provided. E.g., in vitro fertilization, plastic surgery reconstruction after a mastectomy. These are big-ticket items, public now expecting these are routine. Easy for HMO to become bankrupt by a few patients running up millions of dollars.* (Health care provider)
- *20 years ago, the basic package was major medical, not sure of the definition, with X percentage paid by the individual. Over the years this has been changing, due to regulations. E.g., having to carry maternity benefits even though only one or two employees will need it. Hard to get back to the basic medical plan.* (Business owner)

2. General health insurance policies. In considering the concept of a minimum benefit, focus group participants were often divided between two camps: those who felt that a major medical/catastrophic type plan with provisions for preventative care and prescription drugs would be sufficient vs. those who believed in the value of a comprehensive plan that covered many of the benefits that are covered in modern plans. In particular, those with awareness of KidCare believed that a similar plan for adults would be of good quality. A minority of participants believed that a managed-care style plan would be necessary to avoid abuses.

Representative quotes:

- *Managed care is okay. I've been in it before. We hear too many bad things about it but it isn't that bad.* (Uninsured person)

- *Complete health perspective – physical, dental, vision, mental – mental illness (depression) affects everything else. Preventive also includes mental health because it (mental wellness) affects so many other things. (*Health and social service representative).
- *I think that if they pass laws for mandatory health insurance, employers should only have to cover catastrophic. The employees should cover the extras. Groups should be able to get a good price for this, but it will force the employer to go out of business if the employer has to pay for all of this.* (Business owner)

3. Specific benefits. Many times focus group participants and interview subjects commented on specific types of benefits they thought should or should not be covered in a minimal health insurance plan. Most focus participants agreed that dental care, especially coverage for bi-annual check ups should be included in a basic health plan. Interview subjects were split on the issue of dental care. There was even less consensus on mental health. Whereas some participants, especially providers and social service professionals believed in the connection between good mental health and general health, others believed that mental health should not be in a minimal policy. A common explanation was that only a small proportion of individuals require mental health benefits, whereas everyone benefits from dental care. Including prescription benefits was a popular topic with many focus group participants believing that some accommodation for the rising costs in prescription medicine would be necessary. However many voiced concerns that such costs need to be contained in some way. Rehabilitation and vision

benefits were mentioned occasionally, but there was no overwhelming concern that these benefits should be included in a minimum health plan.

Representative quotes:

- *Dental insurance was the first that focused on prevention. Dental policies that paid 100 of bi-annual benefits. People take advantage of this and as such their overall dental health is better.* (Insurance representative)
- *Mental should be part of some medical, but we have a long way to go to clarify this area.* (Provider)

I. Funding mechanisms: Affordability

How to pay for mechanisms that will help close the health insurance gap was an important concern among focus group participants. Although it is important to consider solutions to the health insurance gap, many people had different ideas on how such solutions should be funded. Themes were categorized into issues surrounding affordability, changing cultural expectations about health insurance, considering global approaches, such as universal health care, and helping to solve problems with the current methods of reimbursing health care costs.

1. Maintaining affordability. The bottom line to any solution to funding comprehensive health insurance programs is that it remains affordable. For both individuals and businesses that pay the lion share of the premiums, costs need to be kept reasonable. Thus, both parties are concerned about reasonable deductibles and premiums. However, when we talked to potential beneficiaries of expanded health insurance benefits, i.e., the uninsured, many emphatically emphasized that they would want to

contribute to the cost of health insurance expenses through a reasonable premium, up to about 5% of the household income, or through an affordable deductible. No one felt they should receive health insurance benefits for free. A sliding scale seemed to be the most efficient way to establish an equitable reimbursement schedule. Finally, business owners, insurance agents, and health care providers alike discussed the need to control costs by finding ways to bring the cost of health care under control. A common sentiment was that expensive, experimental, unreliable, or otherwise optional therapies should not be covered by health insurance. Nonetheless, there was much "finger pointing" in attributing blame to the rising cost of health care. Insurance agents and business owners often pointed their finger at health care providers and the pharmaceutical industry for frivolously raising health care costs. Providers pointed their finger at the insurance industry for being too profit oriented and not understanding the medical decisions that doctors make day to day. Much blame was placed on the legal system that allowed patients to sue doctors for seemingly innocuous medical mishaps. Finally many focus group participants, including the uninsured pointed their fingers at public health insurance recipients for abusing "the system."

Representative quotes:

- *How much could I save if I need to buy milk? If I could afford, would already have insurance.* (Uninsured person)
- *There should be some charge, even if it's small. It can't be free because someone has to pay for it. It has to be paid by someone in order to keep going..* (Uninsured person*)*

- *It's the business; it's not the people. It (the cost) should be regulated..* (Local government representative)

2. Changing expectations. Most of the stakeholders of the health insurance dilemma had concerns about the "take it for granted" attitude that pervades our society. With regard to health care and health insurance this sentiment seemed to manifest itself in two ways. First, there was a call for better patient responsibility in attending to health care regimens, such as showing up for appointments, taking prescribed therapies, and not delaying treatment. To the extent that many, concerned stakeholder groups are working hard to make health care available and affordable, they felt that recipients should do their part to actively participate in these efforts as a responsible patient. Second, many felt the desire to educate young people about the importance of health insurance so they develop expectations from an early age that they are ultimately accountable for their health and for having health insurance.

Representative quotes:

- *Patients don't want to do what they need to do. They want a pill to cure the problem. There needs to be more responsibility put on patients.* (Provider)
- *Health education classes/seminars might also work as an incentive – if they attend these classes their premium can be reduced, etc.* (Health and social service representative)

3. General Systems. With regard to mechanisms to fund health insurance initiatives or to making health insurance more affordable, there was considerable discussion about overarching systems that would manage costs and access to care. In

general, focus group participants expressed opinions about two such systems: managed care and universal health care (i.e., single payer). Both systems generated strong opinions both for and against. With regard to managed care, participants were concerned about the lack of autonomy, both from the provider's perspective in making medical decisions and from the recipient's perspective in choosing providers. Nonetheless, many believed that managed care systems, such as health maintenance organizations (HMOs) are necessary to control costs and thus broaden accessibility to health care. With regard to universal health care or a single-payer system, many participants (but certainly not all) felt that such a system might be the only way to truly make health care accessible to all people. The belief was that as long as multiple profit- and non-profit oriented entities are competing for health care dollars, there would always be holes in the system. The countervailing sentiment, however, was that universal health care would be too expensive and that the business owner and the tax payer would end up footing a larger portion of the bill for health care than they already do. Furthermore, many held the impression that universal health care systems that are in place in other societies are failures. An oft-sited example was the long waiting lists for surgeries and other treatments that people in foreign companies had to endure.

Representative quotes:

- *I had to change doctors for my child, but I was happy to do it because of the fact that my children are now insured [through a managed care system]*. (Uninsured person)
- *Single-payer is perceived to be the solution, but this will put a lot of people out of business like local pharmacist. (*Provider*).*

*Already many insurance companies are dropping out of the health insurance business because it's not profitable. (*Insurance representative)

- *Some other countries take care of their citizens and provide care. Ours should too.* (Uninsured person)
- *A voucher based or subsidy based program for health insurance, paid directly to health insurance companies might be a worthwhile idea.* (Insurance company executive)

4. Problems to consider. Although focus group participants were asked to consider ways to fund expansions to health insurance, inevitably they wanted to call attention to problems with the "current" system. The following themes emerged:

a. **Stigma of public health insurance.** To the extent that efforts to close the health insurance gap will involve expansion of publicly funded health insurance programs, such as Medicaid, focus group participants had concerns about the stigma of public aid. Often, it was mentioned that service providers and their staff who seemed to have preconceived negative attitudes toward public health insurance recipients reinforced this stigma. Uninsured people were especially concerned about being prejudged for utilizing public health insurance programs.

Representative quote: *The biggest issue is really the stigma attached to being enrolled in public assistance programs*. (Health and social service representative)

b. Tax incentives good for business but not individuals. Many, but not all business owners held favorable attitudes toward tax incentives, especially tax

credits, as a way to encourage employers to provide health insurance to employees. Business owners strongly preferred a tax break for business owners as opposed to a tax burden to fund public health insurance expansion. On the other hand, many focus group participants, especially the uninsured and social service providers, believed that tax incentives would not be encouraging to the working poor who are without health insurance. The common sentiment was that the tax burden for the working poor is already low and a tax incentive would not be perceived as very valuable.

Representative quote: *Businesses will respond to incentives. The people who are uninsured don't file tax returns and won't see a tax benefit. Employers do. And will benefit more from those types of incentives.* (Insurance representative).

c. Complications of medical savings accounts. Just as many worried that tax incentives would not appeal to the typical person who lacks health insurance, many also believed that medical savings accounts would not be effective. The concern was that such programs require the ability to plan and to accurately forecast an individual's or family's yearly medical expenses. Furthermore, many felt that the hassles of sending in receipts for reimbursement might overwhelm many people. Finally, many people felt that they or people they knew would experience hardship by having a certain portion of their already small paycheck set aside for potential medical expenses.

Representative quote: *People who don't think about the future would not take advantage of medical savings accounts.* (Uninsured person)

d. Problems with mandates. Many times we heard concerns that government mandates to cover certain types of procedures, especially on essential

procedures applicable to only a small minority of recipients keeps the cost of health insurance high. Business owners were especially outraged at having to pay for benefits that their employees did not need. They would much prefer to make such benefits optional.

Representative quote: *If mandates are added to the problem, it causes prices to rise; example [analogy] is minimum wage – no one discusses the ripple effect of these types of policies* (Insurance representative).

e. Reimbursement to providers. Health care providers were often frustrated by the complications of getting reimbursed in a timely and equitable manner from both public and private payers. Whatever mechanism is used to expand health insurance benefits, providers wanted to make sure that it did not add to the burdens they already experience with fair and timely reimbursements. Furthermore, providers did not want to be forced to accept a sub-minimum reimbursement system that would cause them to raise their rates for other patients.

Representative quote: *Medicare is responsible for high costs due to capitation. Forces providers to have high rates because they know they'll only get half back. They have to charge this same rate to the general public.* (Insurance representative).

J. Raising awareness/marketing

One question we asked uninsured focus group members was what sources of information are you most likely to pay attention to when it comes to getting information about health insurance options and medical care. It was acknowledged by virtually all of these focus group members that given the complicated structure of the public health

insurance system, the amount of misinformation circulating about, and the cultural and/or language barriers that many face when confronting a medical situation, a concerted, coordinated, and systematized campaign is necessary to raise awareness of the various options presently in existence. No single source of information rose to the top as most credible or likely to be accessed by the majority of the uninsured. Rather, using multiple sources was seen as the most likely way to mount a successful information campaign about health insurance options.

Representative Quote: *The structure and implementation process are problems. For example, people often ask "Where do I sign up?" and "Where do I got to learn about the program?"* (Rural health clinic director)

1. Multiple sources - general. The uninsured we spoke with had varied habits in terms of television watching or radio use. Public service announcements were seen as important vehicles for information, including Spanish TV and radio. However, many who worked or watched little TV said this mechanism would not be terribly useful. The telephone book could be used to place information about public programs. Campaigns or information booths at public schools were seen as very practical mechanisms for targeting uninsured families with children, especially if this outreach was done during the registration process at the beginning of the school year. Community outreach was also seen as an effective and credible way to apprise people of their health insurance options. For example, institutions such as the Salvation Army, churches, and other community programs should have this as part of their mission to actively work to discover who the uninsured are within their respective communities and to help link them with appropriate resources, such as KidCare. Other highly visible mechanisms

mentioned were billboards, grocery stores, newspapers and magazines, and even advertisements on milk cartons.

Representative quotes:

- *Salvation Army does a lot of outreach with KidCare – making people aware of it and it's services. 80 families in the tri-cities applied for it, but WITH a KidCare representative/worker – they would have never done that on their own though, because it's just too complicated* (Health and social service agent).
- *I found out about KidCare from a national magazine. I doubted that I would qualify for it. I finally learned more about it at the state fair and finally applied* (Uninsured person).
- *I know they advertise on TV now. I see it on billboards, WIC offices, doctor's offices, and even the grocery store* (Uninsured person).

2. Multiple sources - health services. Many uninsured pointed out that all doctor offices should provide information in the way of pamphlets and brochures about medical services available to the uninsured. Several said that hospital emergency rooms should also carry information about available services, because for many uninsured, the emergency room is the first contact they have with a medical provider. Health and social service organizations and health departments were obvious places where credible information could be obtained

3. Employers and the government. Some focus group members said that receiving an official letter from the government about their options for health insurance

would make them sit up and take notice. Some participants said they did not trust media like TV, radio, or a telephone or direct-mail campaign, because they would believe there was likely a "catch", and they didn't want to risk being victimized by a non-legitimate source. Telemarketing was seen as a particularly disreputable way of providing information.

These same members, as well as others, said that an employer would be seen as a credible source of information about public or other options for health insurance programs, even if that employer did not offer health insurance. They perceived their employers as trustworthy sources of information about what options they *do* have. Representative Quote: *When I hire people at my hotel job, we tell them about the local programs like KidCare. I have several single parents who now know how to find help* (Uninsured person).

4. Word of mouth. For many individuals who have been in the public health insurance system for a long time, word of mouth is the most reliable source of information. These individuals "know the system", know its limitations, and even know how it can be manipulated. This "insider network" benefits people who move to a new location to join family members already residing there who have figured out what services are available and how to access them. Clearly this information mechanism is insufficient for community newcomers who are not part of a ready-made network, and a concerted and well-orchestrated information campaign is what is necessary to help bring these people "inside the loop".

V. Research Findings - Nominal Group Process

In addition to listening to people's experiences and gathering opinions and perceptions about the range of health-insurance issues addressed in this study, we also wanted to gather their ideas for solving the health-insurance gap. Therefore, at the conclusion of many of the focus group interviews, we transitioned to a different format called a "nominal group process (NGP). This technique allowed participants to brainstorm ideas for solutions to address all or part of the factors that affect the health-insurance gap. Participants also rank-ordered the suggestions.

One disadvantage to this process is that ideas generated during a particular session did not necessarily carry the same "weight" in terms of specificity, magnitude, or feasibility. This made ranking the ideas somewhat problematic as participants grappled with the task of trying to prioritize concepts that were inherently super or subordinate to other concepts in the list. This problem was alleviated in part by using the group process to combine, synthesize, and integrate ideas that were related, thus reducing and hopefully equalizing the number of ideas to be ranked.

Another problem inherent in the nominal group process is that ideas generated within one group may be inconsistent with other ideas generated by the same group. When this occurs across groups, contradictory themes emerge. The nominal group processes that accompanied the focus groups resulted in approximately thirteen overarching themes, several of which are incompatible with other themes that emerged. The themes are as follows.

A. Focus on cost control measures through government mandates.

Much of the discussion in the focus and nominal groups concentrated on coming up with measures for stemming the spiraling costs of medical care. There was a good deal of sentiment that rising medical costs accounted for much of the rapid increases in health insurance costs experienced by many small business owners. Some nominal group participants felt that the medical profession had gotten too greedy, whereas others pointed to mushrooming litigation threats and the concomitant rise in malpractice insurance premiums as primary sources of increased medical costs. Although there was reluctance on the part of many participants to entrust government with much responsibility for breaking the cycle of rising medical and insurance costs, one common sentiment was that the government, either state or federal, was the only entity large enough to intervene and control costs.

B. Government mandates to insure that everyone has access to affordable health insurance.

We heard from many group participants, the uninsured, small business owners, health and social service agency representatives that health insurance is out of reach for many people because of its cost. They did not subscribe to the notion, as some insurance representatives did, that health insurance is technically available to everyone, pointing out that health insurance is certainly not available to people who have to choose between insuring their family and feeding their family. Once again, some group participants looked to the government for holding down costs of health insurance so that everyone, regardless of financial status, could afford a policy that would protect them and their families in the event of medical crisis.

C. Reduce government mandates regarding required benefits.

Although it is true that many nominal group participants argued for a government role in placing a ceiling on rising medical and insurance costs, there was also considerable sentiment, particularly among small business owners, that government mandates requiring certain benefits not only contributed to those rising costs, but also removed a decision-making role from the business owners. Several business owners complained, for example, that they were required to provide maternity benefits even though they had no female employees of childbearing age. They felt these mandates were an unnecessary intrusion of the government into their business affairs and expressed considerable resentment over this fact.

D. Education about the appropriate and realistic role of health insurance.

One theme that was common across many groups, from business owners to health-care providers to insurance agents was that many people seem to have a grandiose idea about, or sense of entitlement toward, health insurance. Many participants were frustrated with the feeling that others seem to think that health insurance should cover all ills for all people at all times, and that a high standard of medical care was a right in our society. Participants also believed that our society had lost a sense of personal responsibility for providing for one's health-care needs. Several participants called for some kind of on-going education of our citizenry regarding the role of health insurance in maintaining a healthy population. Ideas ranged from requiring the study of health insurance and related topics in public schools or colleges, to apprising employees of the

dollar value of their health insurance benefits as a way of conveying the true cost of medical care.

E. Increase, improve, and make more efficient public systems of health insurance.

Virtually all of our nominal group participants commented on the bureaucratic nightmare of fielding the public health insurance maze. Insurance agents complained that KidCare applications were impossibly complicated with little financial incentive for the broker to facilitate. They also felt that Medicaid eligibility rules resulted in people shifting between different programs or being on or off public aid, compounding the problem of paperwork. Complaints were also heard about unreliable ICHIP funds or the premiums impossibly expensive. Doctors complained of the need to hire extra staff just to sort through the web of paperwork. A host of other stories surfaced that all seemed to point to an inefficient, cumbersome, and overly bureaucratic public health insurance system.

F. Tort reform.

While there was much finger pointing about the sources of rising medical and insurance costs, there was general agreement among the participants that physicians' fear of being sued and the corresponding tendency to provide an umbrella of medical services in order to cover themselves was a major contributor to unchecked medical costs.

Many participants felt that our progression into an overly litigious society has created an environment of fear within the medical community that has resulted in the need for self-protection through massive malpractice policies. This cycle has also contributed to a growing sense of entitlement among patients that not only should all

medical outcomes be perfect, but that we should be fully compensated if they aren't. Many participants, particularly medical providers felt that returning to an environment in which doctors could practice medicine without the fear of reprisals for honest mistakes would remove one of the major factors leading to skyrocketing medical costs, thereby making health insurance more financially feasible for many.

G. Insurance industry to administer and develop state health insurance programs.

Many insurance representatives expressed concern that an increase in government insurance options in order to reach a greater percent of the uninsured would increasingly leave the insurance industry "out of the loop," thus paving the way for a public health insurance plan that would spell the end of privatized heath insurance. Perhaps anticipating what some believed to be an unstated agenda of this project to move towards a state or national insurance program, several participants felt that the insurance industry should be tapped to develop and administer any state-run insurance programs. The feeling among these participants was that the insurance industry could administer a large insurance initiative far more efficiently than states or the federal government would. Moreover, this move would afford a continued role for the insurance industry, albeit with increasing emphasis and stake in the public sector.

H. Everyone contributes his or her "fair share."

One recurring theme was the concept of contributing a "fair share" towards one's insurance needs. Among nominal group participants this theme was particularly prevalent among medical providers and insurance representatives who provided numerous examples of individuals who preferred to take calculated (or sometimes

uncalculated) risks on the assumption that the pubic system would "bale them out" if necessary. Medical providers and insurance representatives both pointed to each other as being unwilling to cut into their respective profit margins, that is, unwilling to invest their "fair share" in order to break the cycle of unchecked costs. We heard from business owners who reported stories of employees who used insurance benefits to negotiate jobs, thereby taking the opportunity to place the burden of their "fair share" on the shoulders of their employers. The concept of "fair share" was apparent by all participants who recognized that cutting into the unmitigated cycle of rising health care costs was a responsibility that needed to be borne by everyone.

I. Local control of medical decisions, and access to local providers.

There was general sentiment among many nominal group participants that managed care removes much medical decision making power from health care providers and places it in the hands of an ill-informed bureaucracy where the bottom line takes precedence over medical judgment. Doctors felt their inability to practice medicine without being confined by HMO regulations contributes indirectly to the cost of health insurance because of the multiple bureaucratic and logistical hurdles that must be negotiated in order to provide basic care.

Added to this was the frustration expressed by many participants, particularly small business owners that the need to stay abreast of shifting HMO regulations, mushrooming premiums, and changing benefit packages made it difficult or impossible to stay with one provider or another, thereby removing employees' access to those providers. Any mechanism to improve access to health insurance, they felt, had to make it easier for medical providers to practice medicine without being encumbered by

questionable regulations, and for patients to have greater say in their choice of health care providers.

J. Prevent undue penalizing for pre-existing conditions.

Small business owner participants told of being subject to precipitous rises in premium costs: 20%, 30%, 40%, even 60% in the case of one participant. These costs were often due to a medical condition of one employee, the insurance premium cost of which was then passed on the rest of the employees. Several participants said that even medical conditions that were well managed or not medically significant were often a red flag to insurance companies, resulting in huge premium increases, reductions in benefit packages, or both. Several business owners expressed bitterness that years of good faith negotiation with insurance companies and a record of no medical claims did not seem to account for anything if an employee got sick. While most business owners understood that age and its attendant infirmities necessitate a different scale of insurance requirements, they felt their entire workforce should not be penalized for the illness or a pre-existing condition of a single employee. Several participants felt that insurance companies should not have access to employee medical records, that premiums should be based on the age profile of the employee pool, and nothing more.

K. Purchasing pools and tax incentives for small businesses.

There was general agreement among business owners that they would welcome some mechanism for helping to reduce their monetary burden for carrying employee health insurance. Although most participants were unaware of the Illinois state law that permits employers to pool their companies together in order to form a purchasing group or alliance, focus group discussions about purchasing pool feasibility stimulated several

business owners to cite purchasing pools as one method for helping to close the health insurance gap. Nonetheless, several participants realized the inherent danger that purchasing pools could quickly be reduced to high risk pools for employees who are otherwise uninsurable, and that some measures would have to be taken to create a large enough pool in order to sufficiently distribute the risk.

There was less consensus about tax incentives as a mechanism for counterbalancing the cost burden of health insurance to small business owners. Although several business owners said they would welcome a tax rebate in addition to the health insurance tax credit they already receive, others wanted nothing to do with any government compensation, claiming that the strings attached would make the incentive more trouble than it was worth.

L. Separate health insurance from employment.

Although most small business owners we spoke with felt committed to their sense of social responsibility in providing health insurance to employees, and looked upon providing health insurance as a necessary tool for attracting and retaining good employees, some medical providers and health and social service agents felt that business owners had different attitudes toward health insurance. Many of the uninsured, these participants argued, constituted the working poor, people who work seasonal or several part-time jobs, thus exempting their employers from providing many of the benefits that full-time employees enjoy. They felt that such critical needs as health insurance should not be left to the vagaries of employment and other economic cycles, that another mechanism providing for a more reliable vehicle was needed to ensure across-the-board

coverage for people who are not otherwise fortunate enough to receive insurance benefits through their work.

M. Universal health care/insurance.

With the exception of business owners, the rest of the groups contained at least some participants who favored some sort of universal health care or universal health insurance. This was not seen as an ideal solution, and several participants suggested this solution with the recognition that some degree of health-care rationing was necessary in order to provide equal access to a large population. Many people were quick to point out that rationing takes place already, but that this rationing is based on ability to pay. With all of its pitfalls, many participants saw some kind of universal approach, either through public insurance or by creating a universal health care system, as the only viable means for providing affordable and reliable access to health care everyone.